

# Exchange

ON HIV AND AIDS, SEXUALITY AND GENDER



## How to realise community involvement in programme implementation

By Sabrina Erné and Mariëlle Hart

Experiences over the world demonstrate that the involvement of communities in HIV and AIDS interventions greatly contributes to the effectiveness of programmes. Moreover, international actors recognise the importance of community involvement through community mobilisation and community systems strengthening.<sup>1</sup> This edition of the *Exchange* magazine highlights some recent developments and examples of participation by communities in programmes that respond to HIV and AIDS. These are provided by STOP AIDS NOW!, a non-governmental organisation (NGO) that works towards a world without AIDS, in close collaboration with various other organisations, governments, and communities from different regions of the world.

'Community' is a widely used term with no single or fixed definition. Diverse and dynamic, communities are formed by people connected to each other in distinct and varied ways, such that one may be part of more than one community. Living in the same area, sharing experiences, health and other challenges, living situations, culture, religion, identity or values, are all aspects of community membership.<sup>2</sup> Community involvement may range from collective responses driven and led by communities, and supported with their resources, to their "co-option" by external actors, with various degrees of consultation, participation, and mobilisation. Community involvement in HIV and AIDS interventions has successfully been done throughout the world for years, but was rarely described as 'critical' for effective HIV and AIDS programming.<sup>3</sup>

"The ultimate test for successful community involvement is when people are able to be altruistic and look beyond themselves and say: I will take certain actions *for the sake of my community*. Not because of a policy or a programme, but because there is a community feeling. Then you have the larger societal good in place. That is the essence behind some of the community initiatives that we take forward," states Peter Ellis, Africa Regional Director for the Southern African Development Community (SADC) Region at the Clinton Health Access Initiative.

### Frameworks to fill gaps

Recent frameworks developed by international actors support community involvement. Both the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund)<sup>4</sup> and the Joint United Nations Programme on HIV/AIDS (UNAIDS)<sup>5</sup> emphasise that active participation by NGOs and community-based organisations (CBOs) is vital for the implementation of effective HIV and AIDS interventions. CBOs are generally those organisations that have arisen within a community in response to particular needs or challenges and are locally organised by community members.<sup>6</sup>

The framework developed by the Global Fund is the Community Systems Strengthening (CSS) Framework<sup>7</sup>, which can be used by all who aim to improve community health. CSS interventions aim to reinforce community systems to enable people to make use of local services, networks and key figures in order to improve their well-being and health. The CSS Framework outlines the core components of strong community action to facilitate increased funding and technical support. The Framework, for instance, stresses that CBOs, key affected populations, and communities should have a significant and equitable role in all aspects of programme planning, design, implementation and monitoring. Moreover, programming needs to be developed based on human rights, including the right to health and non-discrimination.

## Editorial



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### Involving communities for HIV project sustainability

Community involvement has played a key role in initiating and sustaining initiatives since the advent of HIV. Compelled to act in the wake of a devastating disease, communities agitated for individual and policy change that ultimately led to the creation of community-based organisations (CBOs) that initiated educational, HIV prevention and care interventions targeting affected populations.

Communities can be defined by geographical area or by shared characteristics or interests. The terms community "involvement" and "participation" are often used to imply one and the same thing although the degree of involvement varies. According to the WHO, community involvement focuses on contributing in developing health policies and strategies to promote communities' ownership and participation in the health system; building institutional and individual capacities in countries for community participation, organisation and management of the health system; contributing in institutionalising monitoring of community-based health activities; increasing awareness of countries and advocating for mainstreaming community ownership and participation in national health policies and health strategic plans and supporting countries to strengthen coordination of and collaboration with civil society organisations particularly CBOs in community health development.

Meaningful community involvement in health services contributes to more effective and sustainable programmes that are responsive to clients' needs. It is, therefore, imperative that programme implementers involve communities in initiatives from project identification, implementation, monitoring and evaluation. The starting point of such involvement may include exploring community norms and values; assessing and making use of existing community resources; including sources of social influence; working through social networks and fostering family and social support. Also critical is harnessing the collective power of women as agents of change in the community; creating synergy between health facilities and community-based sources of information and services and addressing the broader context within which community involvement is promoted.

While designing services and messages for HIV prevention, programme managers should factor community opinions, which should be gathered and shared among relevant players to ensure success and effectiveness. Moreover, community participation must include consistent and open-minded engagement throughout the intervention, with careful planning of how communities will continue to be engaged beyond a specific project's life.

Research has shown that programmes that involve community members in developing, implementing, and monitoring activities are more likely to be acceptable to the community, to have more effective outcomes and to be sustainable. Conversely, failure to involve the community may not only result in a failed intervention, but may also produce unforeseen and possibly adverse effects. In addition, community involvement can positively affect community norms and contextual factors to create an environment favourable to changes in behaviour that may decrease the vulnerability of individuals and groups at risk within the community. ■

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The other framework has been published in *The Lancet* in 2011<sup>8</sup>, it is the Strategic Investment Framework for HIV Funding and Programming, developed by UNAIDS. The Strategic Investment Framework shows how to better target HIV programming and curb spending on HIV over the next decade (see Figure 1). The Strategic Investment Framework enables countries to focus funding on efforts that make the most effective use of scarce resources. It is a useful tool for analysing the gaps and opportunities for governments and service providers like the UN, in order to be more effective. It recognises that partnerships between different organisations, communities, civil society organisations, and governments are critical to the development of programmes that ensure human rights and access to services. The Strategic Investment Framework provides an evidence

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based and costed case for doing more of what has already been done in order to reach a critical point where the need for programmes and services will decline. It provides an increased focus on value for money for the community response to HIV and AIDS. The Strategic Investment Framework emphasises that community mobilisation is a core component of an effective HIV response, and clearly assumes that placing greater emphasis on community mobilisation will enable key efficiency gains and impact. Accurately linking the different pieces of the 'puzzle' is crucial for the success of this multi-stakeholder approach, as *Figure 1* clearly demonstrates.

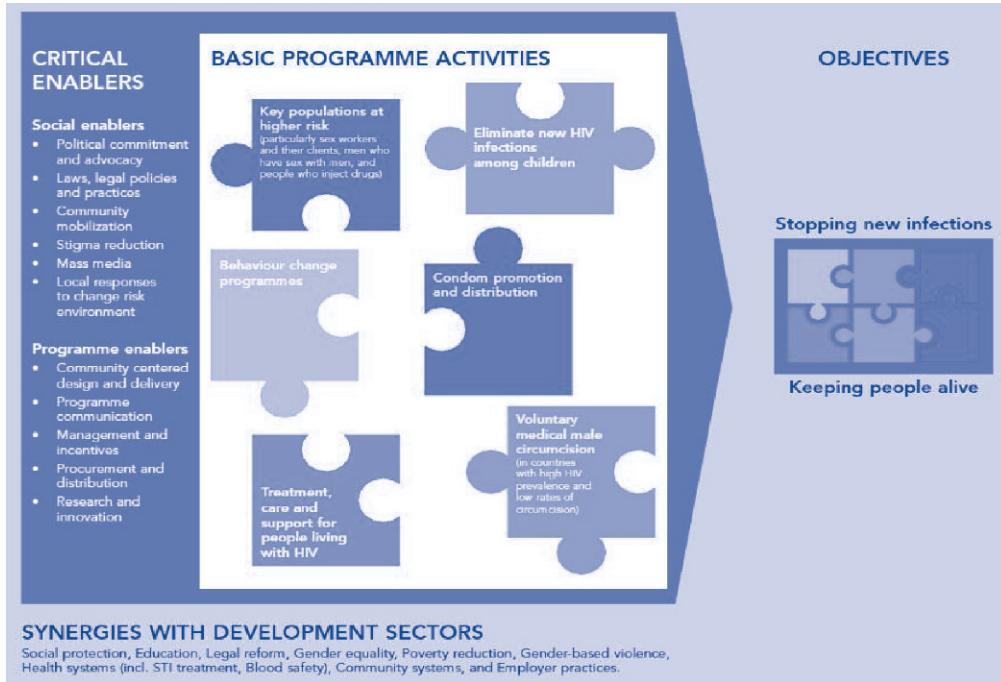
**Implementing the Strategic Investment Framework**

National governments and their partners can apply the Strategic Investment Framework to guide HIV responses and make the most of their programmes. The pioneering programme 'Maximising ART for Better Health and Zero New HIV Infections' (*MaxART*) in Swaziland, illustrates the appropriate implementation of the principles of the Investment Framework. Jointly with the Swaziland Ministry of Health – which leads the programme – and the Clinton Health Access Initiative, STOP AIDS NOW! initiated *MaxART*, which runs from 2011 until 2014. It shows how community mobilisation enables key efficiency gains and improves impact. Organisations that represent various disciplines collaborate in *MaxART*, and several activities to mobilise and support communities around health issues are brought together in the programme. The ambitious goal is to improve the lives of all people living with HIV in Swaziland - the country



Photo by Adriaan Backer.

Figure 1: Proposed Investment Framework<sup>9</sup>



with the highest HIV prevalence in the world - and eliminate new infections. Regular testing, access to early treatment, and lifelong retention in care and treatment are key elements of *MaxART*. STOP AIDS NOW! encourages the strong involvement of communities through CBOs and NGOs, which are the backbone of the *MaxART* programme.<sup>10</sup>

Networks of people living with HIV help to ensure that the components of the *MaxART* programme are relevant, respectful, and useful for the people they impact most. The government of Swaziland needs to have insight in what does and does not work for people living with HIV, when it sets up services for them. Global and local networks of people living with HIV provide STOP AIDS NOW! and the Clinton Health Access Initiative with information about the experiences of people living with HIV, and monitor the scaling-up of HIV testing, care, and treatment, to ensure that it continues to support the human rights of all Swazis.

Ellis: "It is the objective which makes the *MaxART* programme unique. I do not know any other country that has set the goal to ensure a conducive environment that promotes complete health and reduces new HIV infections. Even the global goals of the UN and WHO that state that countries should achieve universal access to treatment, which is defined as a target of 80 per cent, are very ambitious. But we have decided to even stretch that target and try to achieve at least 90 per cent access. That in itself might have a halo-effect on prevention."

UNAIDS data show that Swaziland already has had success in getting more than 70 per cent of those who need treatment on treatment.<sup>11</sup> Ellis: "But somehow I think that getting from 70 to 90 per cent or more may be even more difficult than getting from zero till 70. We felt that we could make a difference in getting the country over what might be called 'the last mile of the challenge.' The *MaxART* programme does not employ a lot of scientists who are the world's leading thinkers, but taps into the world's experts. Within the programme, many different partners collaborate, including a large number of community-based organisations, such as networks of people living with HIV. It is about bringing them all together and integrating what makes the *MaxART* programme distinctive. The programme is not distinctive in only one vertical area."

**Community responses**

In addressing the HIV epidemic, community involvement has always played a central role in generating individual and social change. Volunteers and activists were the first creators of community-based organisations. Community responses have developed as the epidemic has evolved, according to the World Bank. Non-governmental organisations working on HIV and AIDS issues in Brazil, for instance, initially focused on fighting social exclusion and pressuring the government to be more responsive. Their focus has shifted to, amongst other things, developing home-care programmes and establishing HIV support groups. Another global development is related to treatment. As treatment has become more widely available, CBOs have increased their involvement in treatment-related activities, and many have changed the focus of their work. In South Africa, for example, the Treatment Action Campaign, a South African AIDS activist organisation which was founded in 1998, has expanded its actions on treatment access, to also include mobilising community involvement in treatment education and treatment adherence.<sup>12</sup>

The World Bank states: "Countries and regions have different historical trajectories which have resulted in the development of particular civil society contexts and different manifestations of civil society."<sup>13</sup> Civil society organisations, including CBOs, represent community members and their aspirations. Broad regional similarities have been noted between community-based response to HIV in Anglophone African countries, with greater numbers of associations organised in a decentralised manner, and faith-based groups playing a key role in health care. This can be compared with West African Francophone countries, which tend to have more compact community-based groups, based on standard service delivery models. North African countries in turn tend to have fewer community-based organisations involved in HIV-related activities, likely as a result of a lack of overall community and civil society development."<sup>14</sup>

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**STOP AIDS NOW!**

**STOP AIDS NOW!** works towards a world without AIDS through:

- Integrating the response to HIV into development cooperation;
- Innovative working methods and forms of collaboration; and
- Fundraising, campaigning and lobbying.

**STOP AIDS NOW!** advocates for stronger support of community systems strengthening in global health and HIV and AIDS policies. At the international level, **STOP AIDS NOW!** works with the International HIV/AIDS Alliance, in the Stop AIDS Alliance, to promote the Community Systems Strengthening Framework and the Investment Framework for HIV Funding and Programming as important models to operationalise the active participation of communities.

At programme level, **STOP AIDS NOW!** emphasises local ownership and a participatory approach, which is community-based and, thus, culture and context-specific. Partnerships and cooperation with governments, community organisations, and individuals who take responsibility for addressing the HIV epidemic are crucial for **STOP AIDS NOW!**

**STOP AIDS NOW!** is a partnership-driven organisation, founded in 2000 by Aids Fonds and four Dutch development organisations: Cordaid, Hivos, ICCO, and Oxfam Novib.

**Community involvement in Swaziland**

Community involvement in the *MaxART* programme perfectly fits the Swaziland context. The programme's approach is not to create new community structures but to leverage the existing structures in communities from the chiefdoms and formal leadership down to the family and individual level. In order to ensure that people with HIV live longer and healthier lives, it is essential to bring HIV services within their reach. And it is the role of CBOs to bring the people closer to the services. The Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS) works with community partners, leaders, 7,000 volunteers, and many advocacy groups to secure effective coordination within the *MaxART* programme.

To reach all those who need to be tested and enrolled on care and treatment, the communities of Swaziland need to be an integral part of the solution. Lois Chingandu, Executive Director of SAfAIDS, explains that it is important that within communities all members speak the same language. Therefore, the first step is to train the traditional community leaders. "We start with them, because a traditional community leader is a really influential person in Swaziland. People look at him for guidance and he is a role model. Thus he can initiate new things." The training is combined with a discussion on culture, as there are cultural practices that fuel the spread of HIV in Swaziland. "One of the key issues is polygamy," says Chingandu. We explain that the practice itself is not wrong, but that the risk lies in the fact that if one partner is unfaithful, the whole group can get HIV. We emphasise that it is not the place of outsiders like us to judge the practice. But we explain that it then becomes difficult to control."

Part of the *MaxART* approach is to talk about the cultural practices in Swaziland and discuss whether, in the context of HIV, people should continue the practice of having multiple partners. And if so, how polygamy could be made safe. Chingandu indicates that this is the entry point for testing. As the traditional leaders are the gateways to the communities, they are in the position to address the health issues that affect their communities. Once traditional leaders understand the importance, they can motivate the community members to embrace HIV prevention, treatment, care, and support. "It is about individualising the issue and bringing it home in the cultural context," Chingandu adds.

When asked about the obstacles SAfAIDS faces in Swaziland, Chingandu explains that the major challenge within communities is the reluctance to go for a test because of the stigma connected to HIV. This is related to the moral aspect of HIV in the African context. According to Chingandu it is very hard to take away the stigma, as 80 per cent of the inhabitants of Swaziland claim that they are Christians. "If you claim that you live according to Christian values, including faithfulness, and then become HIV positive, people think this raises questions regarding their moral stand in society." In order to overcome stigma, SAfAIDS invests in education to make people understand that there is no reason for shame because anyone Christian or not is at risk of getting infected. SAfAIDS encourages people to go for a test, and if needed get treatment, so people can be alive and raise their children.

Chingandu: "The goal of the *MaxART* programme is ambitious, but failure is not an option. The time is right and we really have to move forward. At present, there is much more willingness to get tested than before, because people know that the government has been supportive in ensuring that treatment is available. We need to continue to strengthen community involvement to create demand for testing and treatment. It is critical."

**Cases of STOP AIDS NOW!**

So, although community responses to HIV and AIDS are different across the globe, practice shows that, whatever their specific contexts, community involvement is critical for the effectiveness of HIV and AIDS interventions. Different tools, such as the Strategic Investment Framework and the Community Systems Strengthening Framework, recognise the role of communities in ensuring better health services, in particular improved HIV services. ■

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**In order to ensure that people with HIV live longer and healthier lives, it is essential to bring HIV services within their reach.**

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